



Housing Options Providing
Extra Support

The Secretary
Senate Community Affairs References Committee
PO Box 6100
Parliament House
Canberra ACT 2600

**SUBMISSION TO SENATE INQUIRY INTO THE FUNDING AND
OPERATION OF THE COMMONWEALTH STATE/TERRITORY DISABILITY
AGREEMENT**

In response to the above inquiry, we would like to submit the following comments relating to:

(b) “the appropriateness or otherwise of current Commonwealth/State/Territory joint funding arrangements, including an analysis of levels of unmet needs and, in particular, the unmet need for accommodation services and support;”

1. Background information

HOPES is a small community based organisation committed to the establishment of appropriate supported accommodation and respite options for Tasmanians (under the age of 65) with acquired disabilities, and neurological conditions. For several years we have sought funds to develop a co-operative living model, as an alternative to aged care nursing home and other inappropriate accommodation options, for this group of people.

Currently ‘younger people’ in Tasmania, who need support for day-to-day living due to neurological disorders or acquired disabilities, have very few options (unless they fall under the Motor Accidents Insurance Board (MAIB) ‘Future Care’ legislation, or have adequate compensation). Due to the inadequacy of current options, people with acquired disabilities are still often kept in acute hospital beds for far longer than necessary, while a ‘place’ (generally inappropriate) is found for them. This not only restricts their rehabilitation, but also adds to the shortage of acute care hospital beds. Although nursing home care is (finally) seen as a last resort, there are still over 150 people under the age of 65 living in aged care facilities, and a continued lack of understanding about appropriate supported accommodation options for people with disabilities.

2. Current Situation

Although CSTDA funds over the past few years have helped to improve respite and recreational options for many, the lack of interface between programs, and the “crisis response” approach to disability issues at state level, continue to offer expensive, often inappropriate solutions, with little reduction in unmet need.

- Traditional group homes are still seen as *the* answer to an accommodation crisis – with little attention to siting on flat ground with level access to community facilities; and only lip service paid to issues of compatibility. Transport in such homes is often one bus, restricting residents to group outings.
- Younger people still living in aged care facilities lose access to community rehabilitation, and funding for appropriate equipment (e.g. self-propelling or electric wheelchairs) – as the rehabilitation and equipment needs become the responsibility of the facility (where funding is allocated on the basis of the needs of the frail aged).
- People with disabilities needing supported accommodation are separated from partners and/or children, and their social networks - there are no places catering for a partner or children. Sometimes this means a partner with a milder disability is left to fend for him or herself in isolation in the community; sometimes it means young children are separated from a parent, only seeing their father or mother when surrounded by other people (with disabilities or frail aged).
- Many people in these situations lose, or are unable to build on or maintain their initial level of independence (because everything is ‘done’ for them – to speed up staff obligations). Staffing levels and resources mean that tasks which residents may be able to carry out, with time and support, are often performed by staff on a communal basis (e.g. preparing meals, simple household chores). In every aspect of life the resident becomes the receiver of care, never a productive member of the community.

3. Respite Options.

- Aged care facilities are often the only respite option available for families caring for a younger adult with disabilities. This situation is not only inappropriate, but the respite bed is often situated in a locked dementia section of the facility. This is because most homes only have one respite bed, and they must be prepared for wandering, demented ‘guests’. To be totally surrounded by people with varying stages of dementia, and to be physically unable to move out of the locked unit, is incredibly stressful for a younger person used to family support in their own home.

- As a result many families opt to forego respite, adding to their overall stress and potentially leading to an earlier need for full-time care for their family member.
- In home respite is only suitable if the parent(s) wish to go away – and even then, can create more stress for the primary carer, preparing the house for the disability support worker to stay.
- Funded programs are generally inflexible, based on the “usual situation” (e.g. they do not cater for people who are in a relationship). Similarly, programs can seldom be combined (e.g. HACC and ISP (Individual Support Program) funds) to cover individual needs.

4. Appropriate Accommodation Options.

It should be the right of every person to have some choice in where they live, and with whom. Although support needs may limit choice for some people, governments and communities should be obliged to ensure suitable options are available.

The recent COAG initiative to “assist young people with disabilities living in residential aged care to successfully move to community based supported accommodation”, and to “improve support services for those remaining in residential aged care” was initially welcomed, but our concerns are now heightened as we see similar inappropriate processes occurring.

It is essential that state and commonwealth governments work together (along with local government, AND stakeholders) to plan and fund suitable alternatives – focussing on the needs of the individual.

Both Commonwealth and State governments have recognised the need to address the issues of an ageing population and disability, but their ‘partnership’ arrangements so far have only amounted to more meetings, research suggestions, and short term projects with strict guidelines. And, once again, the bureaucracy searches for “models” in which to fit individuals.

The underlying problems, current situation, and long-term forecasts are well documented. What we need now are:

- ✓ true partnership arrangements for planning and funding;
- ✓ flexible trial accommodation projects in each state, with long term support built in to those which are successful;
- ✓ genuine input from people with disabilities and their families;
- ✓ a process for individualised funding for respite.

Some alternatives already submitted include:

- A co-operative housing model, including transitional accommodation to enable people to increase their skills and prepare for community living,

while family members are still available to assist (see attached HOPES project).

- A younger person specific unit utilising existing nursing home infrastructure.
- Small group home or cluster unit development with off site support.
- Individual funding packages to enable families to access flexible respite options.

We urge the Commonwealth Government to take a leadership role here, to ensure our younger people with disabilities have the best possible lifestyle, and to avoid a major crisis when the current 'ageing carers' can no longer assist.

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